

Public Health Strategic Thinking Questions to Address Sickle Cell Disease Across the Life Span

Instructions: For each of the following questions, you are asked to provide 3 responses per questions. Answers for each question should be ranked in order of importance.

1. When you reflect on the burden of sickle cell disease, what are the 3 most important issues impacting populations affected by this disease?

Pain/pain-related hospitalizations; Transition/continuing care (system change not burden); Physical limitations; Number of adult system providers; Early mortality/fear of early mortality; Inability to keep job; Myths; Fatigue; Parent compliance and prioritization (immediate needs take precedence: housing, food, etc.).

2. List 3 medical management resources within your agency that could help to address these issues.

New transition clinics; HSA is helpful; SCDA (Education resources); NBS Follow-up; Psychosocial GAP (HSA-most people will see counselor); University of Michigan Gynecological Clinic for patients; Red blood cell exchange.

3. What are 3 underutilized opportunities available for individuals living with sickle cell disease to improve their quality of life?

Compliance adherence; Mental healthcare needs are complex and unrecognized; Hydroxyurea; Transportation; Financial services for prior authorization (affects poor medical management and compliance) the more expensive treatments are, the greater the denials; Sibling matched transplant (HLA typing of siblings); Cord blood collection; Pre-implantation genetic diagnosis costly; IEP 504 Plans (education).

4. List the three most important/critical issues that the Michigan Department of Community Health must focus on and accomplish in the next three years to address sickle cell disease across the life span, and why?

CSHCS beyond age 21; Uninsured adults; IEP 504 plans (MDE); Health insurance quality and access; Employment (who can address this? - i.e. keeping job, education, etc.)

5. What do you see as 3 major opportunities with health insurance to improve the quality and access to healthcare for sickle cell disease populations?

Awareness of services available for patients with SSD; Preventative services

6. If money were no object, what are 3 new services/programs you would implement to address sickle cell disease?

Social work services/resources; Comprehensive sickle cell clinic; patients and physician incentives; Education; Loan repayment-hematologist added for SSD; Fellowship programs for SS only; Training physician assistants and nurse practitioners.